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BREATHLESS

PHILOSOPHICAL LESSONS FROM RESPIRATORY ILLNESS

Havi Carel

It is 12.28. I have just parked my car in a lucky empty space just outside my office. I have a meeting at 12.30. I am texting with one hand and feeling for my inhaler in my coat pocket with the other. I pull the inhaler out, place it in my mouth, and press the pump. Instead of the usual flow of Ventolin, I inhale dust and some particles that feel like pencil shavings. I begin coughing, and choking and spluttering uncontrollably. I cannot breathe. I ramp up the oxygen cylinder by my side to 6 litres per minute – the maximum flow rate my machine allows. But I am still choking and coughing. People walk past and see me coughing. But none of them realise that I need help. This goes on for several minutes. My coughing is so severe, and the wedged particles so stubborn, that I begin to wretch and eventually vomit. I open the car door, and lean over. Someone offers help. Water, I gasp, I need water. I am given water, which rinses out some of the dust, and a few minutes later I am calm enough to remember my meeting. A colleague walks past and I ask him to let the student know that I will be late. By now, I am dirty and wet and I need to go home, shower and change. I drive home, still coughing. Everything takes a long time, because I am now very breathless and my chest is hurting. I look at the inhaler. The cap has come off and the dust must have gotten in that way. I make a mental note to get the car cleaned. By the time I am ready again, I am exhausted. I should lie down, but I don't want to disappoint the student. I refill the oxygen cylinder and drive back to work. I am back parking my car at the same spot at 2pm. It takes me ten minutes to walk one hundred yards up a small hill, stopping every few steps to catch my breath. I am late, again, for the student, but at least I will be there. I have nearly recovered my sense of normalcy. It could have been so simple, I think angrily. Just walk out of the car, up

the stairs and into my office. But what would be a two-minute journey for the healthy has cost me half the afternoon.

This episode may seem minor; but it exemplifies the losses that illness inflicts on the ill person.¹ The ability to rush forward, to press into the day's activities and projects, to habitually and unthinkingly perform small tasks, is lost in illness. The natural flow of events, the ability to accelerate one's pace when needed, the natural rhythm of the day – are all lost. They are replaced by deliberate planning, careful thought, and an anxious awareness of one's body. Respiratory illness forces me to think, carefully, about every bodily motion. When I eat, how much I talk, how many books I can carry, how far I need to walk, how much oxygen I have, how heavy my coat is. Each trivial, previously spontaneous action becomes a fully-blown, carefully planned operation. Each day, as I set out to work, love and live, I do these with complete and continuous awareness of how much breathing will be involved in each activity. Will one oxygen cylinder be enough? If I stop at a store, will there be somewhere to park? Will I get too tired to meet friends for a drink in the evening? I stopped wearing high-heeled shoes, as they are more difficult to walk in. I never chew gum – it interferes with the intricate task of breathing. I don't talk on my phone as I'm walking; it makes me too breathless. At parties I sit down, as chatting while standing makes me dizzy. I constantly have to pay attention to how I am feeling and not let exhaustion, or nausea, or dizziness, creep up on me. A sense of artificiality and explicitness has now replaced my former, carefree being. I still tell myself I lead a full and happy life. But I sometimes wonder whether the myth of normalcy I carefully cultivate within the context of chronic lung disease has been stretched beyond its limits. Acute incidents, like choking, extreme breathlessness, or losing bodily control, puncture the myth with immediacy and force.

The French philosopher Maurice Merleau-Ponty described illness as a “complete form of existence”.ⁱⁱ What might it mean to think of illness as a complete form of life? I suggest that this characterisation tallies with the experiences described above. Illness changes not only the content of the ill person’s day, but also the pace, the way in which activities are carried out, and the way in which she attends to her body during these activities. Illness is knotted into every aspect of every activity. It changes the way in which actions are thought about, planned and performed. Instead of a habitual, pre-reflective, smooth flow of actions, one experiences the day as a string of individually planned, carefully weighed activities, whose importance, demands, and execution need to be carefully assessed. For me, it is a resource problem: oxygen has become a scarce resource. The amount of energy I have is quickly depleted. And so, the ill person is called upon to consider the cost of each action, its desirability, and its feasibility. A friend of mine who underwent a lung transplant nine years ago told me of the real miracle of her new lung: it wasn’t that she was now able to run a marathon, hike up to Machu Picchu, or go scuba diving. The miracle was not in the exotic, the extraordinary. Rather, the miracle was anchored in the mundane, the everyday. The miracle for her was being able to put on her socks by herself. Being able to walk up stairs. Being able to bend down to pick up a pen she has dropped. She regained her bodily freedom and the autonomy that comes with it and this freedom is experienced with most intensity in the freedom to perform everyday actions in an unencumbered, non-reflective way.

The miracle of health is performed in our absence of awareness of it.ⁱⁱⁱ It is a miracle so subtle, so continuous, so taken for granted, that we never notice it. As Leder writes, “while in one sense the body is the most abiding and inescapable presence in our lives, it is also essentially characterised by absence. That is, one’s own body is rarely the thematic object of experience”.^{iv} It is only once health is absent, that it becomes explicitly present for us as a loss. This tacit sense of ability and health enables the natural, pre-reflective freedom to

pursue our aims and goals, and underpins our sense of existence. It is a sense of wholeness, of security, of trust in our bodies.^v And illness makes this invisible health visible. Illness reveals to us the tenuous, vulnerable nature of our bodies, our animal being.

This vulnerability does not have to be understood merely in a negative way. As Alasdair MacIntyre argues, it also expresses our connection with others, our partaking in the exchange of giving and taking, of caring and being cared for, that creates networks and communities, families and friendships.^{vi} Our vulnerable, bodily nature underpins our social relations and our feelings of love and compassion. It also cultivates the sharing of goods: the care we (usually, luckily) receive from our parents we later give to our children, who will go on to give to their children. Our ability to be autonomous is not pre-given but nurtured in us as we grow up. And the ways in which it is nurtured are deeply connected to our bodily needs, our vulnerability, and our interdependent nature. Illness reminds us of this, and in this sense it has an important philosophical and moral role to play.

However, accepting the ‘complete form of existence’ that is illness is very hard indeed. In some cases, illness is curable and can be overcome and possibly forgotten. An example of that kind of illness is a mild heart attack or a broken leg: a temporary disablement followed by recovery. But serious and chronic illness calls for a completely different kind of engagement, of a deeper, more sustained sort. Arthur Frank suffered both kinds of illness. Whilst his heart attack was something he could put behind him, he describes his cancer as an example of the second kind of illness; it made him “sink all the way through and discover life on the other side”.^{vii} This kind of illness is not a medical incident, but a journey. And like any long journey it requires preparation, provisions, and companions. Serious illness deserves serious consideration of the ways in which it changes the ill person’s life and the ways in which medicine may ameliorate these effects. On the phenomenological view I propose here,

illness is an ‘unhomelike being in the world’ turning one’s familiar body and world into a strange uncanny experience. The role of medicine is to restore the ill person’s homelike feeling, and re-inhabit her world with a sense of familiarity and belonging.^{viii}

Changes to the seriously ill person’s entire way of being in the world are often unavoidable and only very partially compensated for through medical interventions and social care. They span changes to the geography of one’s world: places that were near are now far, stairs that used to lead somewhere are now obstacles. Changes to one’s social world: ‘fair weather friends’ may disappear; carefree chats may be replaced by hesitation and silence. I elsewhere described illness as ‘the elephant in the friendship’ because we are so little able to engage with one another’s pain and it is often easier to stay away.^{ix} But intimate, meaningful relationships may become deeper, more authentic, when faced with the challenge of illness and an awareness of the paucity of time. The ill person’s emotional and psychological situation also changes: unexpected resilience may surprise her in times of adversity, but depression and repetitive circular thinking (‘why me?’, ‘If only...’) may also be prominent. Finally, changes to one’s temporal existence: where once a long and happy future was a vague promise, the ill person is now faced with concrete questions of how to deal with and how to deal out time that may be limited, that has an endpoint poignantly attached to it.

Susan Sontag describes illness as ‘the night-side of life’, a different kingdom requiring a passport to enter it from the kingdom of the well.^x She describes the social fantasy in which death and mortality are denied, leading to a sense that the world of the ill is very different, and completely separate to, the normal world of the healthy. This is, of course, an illusion. We all partake in the kingdom of the ill, if not now, in the future. We all begin in utter dependence and we all end there. Transience marks human life. In that sense, the two kingdoms are connected and the transition from one to the other is the one certain fact of

human life as it currently is. The world of the ill is different in many ways to the world of the healthy. Its space and time are different; its limitations obscure possibilities; it requires the ill to live in tense proximity to suffering and death. But the world of the ill is dependent upon the world of the healthy for its norms; and the world of the healthy is dependent on the world of the ill for the aberration of these norms. The two kingdoms mutually imply one another. We always live in both, though we do much to deny this.

It is autumn and the park near our house is covered in dry leaves. The leaves are a warm glow of yellow and orange and brown; they invite to roll in, to throw in the air. My dog is frolicking and running through big piles of leaves, excited at the autumn smells. I see a mother walking past with her two boys. She bends down playfully and stuffs handfuls of leaves down their coats. They laugh and chase her round and round a tree, looking for revenge. She runs around, bending quickly to pick up more leaves, throwing them in the air, racing, chasing and being chased. They laugh and call out to each other. So much air is needed for this, I think. I walk behind them, slowly, observing their playfulness, their physical joy. I share in their joy, their game, second hand, but I am not able to join in anymore. I smile as I trudge up the hill, slowly, slowly, ever mindful of the oxygen so freely available in the air around us and so invisible to those who can have as much of it as they want.

ⁱ S.K. Toombs. "The Meaning of Illness: a Phenomenological Approach to the Patient-Physician Relationship". *The Journal of Medicine and Philosophy* 12 (1987): 219-240; H. Carel. *Illness* (Stocksfield: Acumen, 2008).

ⁱⁱ M. Merleau-Ponty 2012 [1945]. *Phenomenology of perception*. Trans. D.A. Landes (New York and London: Routledge), 110.

ⁱⁱⁱ D. Leder. *The Absent Body* (Chicago: University of Chicago Press, 1990).

^{iv} *Ibid.*, 1.

^v H. Carel. "Bodily Doubt". *Journal of Consciousness Studies* (July 2013).

^{vi} A. McIntyre. *Dependent Rational Animals* (Chicago: Open Court, 1999).

^{vii} A. Frank. *At the Will of the Body*. (Boston: Mariner Books, 1991), 28.

^{viii} F. Svenaeus. Das Unheimliche – Towards a Phenomenology of Illness. *Medicine, Health Care and Philosophy* 3(2000): 3-16; F. Svenaeus. The Body Uncanny – Further Steps Towards a Phenomenology of Illness. *Medicine, Health Care and Philosophy* 3(2000): 125-137.

^{ix} H. Carel. *Illness* (Stocksfield: Acumen, 2008).

^x S. Sontag. *Illness as Metaphor* (London: Penguin Books, 1991), 3.